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ABSTRACT

In the 6 states which comprise Region 5, Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin, there are 23 independent living centers. Programs at these centers are dedicated to the development and provision of a variety of services which assist severely handicapped people to realize the goal of maximum individual independence. These programs have been developed to serve the most significant needs of disabled consumers in each community. General characteristics of the centers are given in tables. Included are major services provided, disabilities served, funding sources, annual budgets, education level of those served, and changes in residential status of those served. The brief descriptions of the characteristics and benefits of independent living centers provide only a sampling of the activities currently taking place in actual operations. Seventeen case studies which feature stories about people and their experiences with independent living centers are included. The studies show comparisons of costs incurred before and after contact with the independent living center and demonstrate the individual and aggregate benefits that are being provided to severely handicapped people by the independent living center. (APG)

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INDEPENDENT LIVING CENTERS

in

REGION V

THE ECONOMIC AND SOCIETAL BENEFITS

of

INDEPENDENT LIVING SERVICES

S0D173433

REHABILITATION SERVICES ADMINISTRATION

U. S. DEPARTMENT of EDUCATION

CHICAGO, ILLINOIS

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INDEPENDENT LIVING

Control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's affairs, participating in day to day life in the community, fulfilling a range of social roles, and making decisions that lead to self-determination and the minimization of physical or psychological dependence on others.

- ILRU Source Book -

A technical assistance manual on Independent Living Research Utilization.

The Institute for Rehabilitation and Research, Houston, Texas
Copyright, 1979

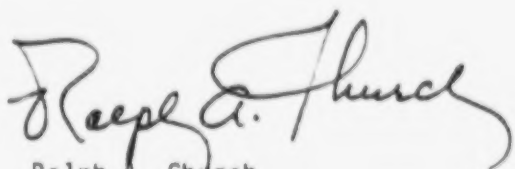
INTRODUCTION

Over the past 50 years the rehabilitation movement has gained recognition as a major force in society's concern for the disabled. During that period of time the emphasis has been almost entirely on vocational rehabilitation or training. Help has usually gone to those who were most likely to become employable, or able to return to work after injury. However, in the last few years there have been increasing expressions by the disabled for recognition of needs beyond employment, such as those related to improvement in their quality of life, the need to be integrated into the mainstream of society or to make meaningful contributions to our nation's well being.

Congress, when amending the Rehabilitation Act of 1973 several years ago, expanded it by adding Title VII, Comprehensive Services for Independent Living. This timely action has brought about great progress toward independence for that part of the disabled population which had previously received little attention and few specific services. Through the authorization of financial support, independent living services to the severely disabled became a reality.

The appropriation of funds to implement Part B of Title VII made possible the establishment of Centers for Independent Living, staffed largely by the disabled themselves. Such services as peer counseling and advocacy, assistance with housing and transportation, personal care assistant programs and independent living skills have thus been made available to the severely disabled.

A brief overview of how those funds have been used over the last three years will be found in the pages that follow. The achievements recounted here have been made possible by Federal legislators who recognized the basic human need for independence and took action. It is a heartening story--a testament of indomitable human courage in the face of what often seem to be insurmountable obstacles.



Ralph A. Church
Regional Commissioner, RSA

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ILLINOIS

Access Living, Chicago

Rockford Access and Mobilization Project - RAMP, Rockford

MICHIGAN

Rehabilitation Institute CIL, Detroit

Center for Independent Living, Grand Rapids

Kalamazoo County CIL, Kalamazoo

Midland Independent Living Center, Midland

Mid-Michigan Urban CIL, Lansing

Northern Michigan Rural CIL, Gaylord

MINNESOTA

Rural Enterprises for Acceptable Living - REAL, Marshall

Rochester CIL, Rochester

Metro CIL, St. Paul

OHIO

Services for Independent Living, Euclid

WISCONSIN

Stout Program for Independent Living, University of Wisconsin, Menomonie

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Theodore J. Witham and Helen Kupper, Project Directors
Helen Kupper, Editor

December, 1982

FOREWORD

In today's world, with its concern for shrinking resources of every kind, everyone eagerly looks for bright spots in an otherwise rather gloomy picture. This is especially so for those in the social service field, who are feeling increasing pressure to justify their existence, particularly in the fiscal area. The "bottom line" is more and more being used as the yardstick against which their work is measured. Is it cost effective? - is the recurring question.

To keep a sense of perspective we must remember that our society views itself as one which traditionally has looked after the less fortunate and has not grudged the effort and the cost. Of late, however, the social and economic climate having changed somewhat, the beleaguered taxpayers expect more accountability and justification for social expenditures.

What follows is documented information to support the position that such expenditures, made through the Independent Living movement, are cost-effective in the best and broadest sense. Many of these vignettes, faithful presentations of data gathered from a number of Centers for Independent Living in Region V, are truly financial "success stories," demonstrating striking reductions in cost after the clients received independent living services. While others may show a cost increase, usually relatively small, they are nonetheless successes. In some cases, the greater outlays represent a short-term expense for training and/or medical and personal-care assistance that will ultimately result in real independence through employment. In still others, what has

been achieved is an improvement in quality of life, giving less fortunate human beings hope for the future and helping those who are unable to help themselves. If any lesson can be drawn from these accounts, it is that there is no single way to assess the value of the multi-faceted Independent Living movement.

Everyone has heard or read that able-bodied people only temporarily possess that happy state, and accident or disease or age will almost inevitably take its toll. When--or if--that day arrives, it will be encouraging to know that Centers for Independent Living and their skilled, compassionate staffs are available for essential services.

Following the profile of Region V CILs are brief stories about consumers who have used their services. The stories are essentially true, though the names are all fictitious, a few details have been changed and locations omitted to preserve privacy.

INDEPENDENT LIVING IN REGION V - A PROFILE

In the six states of Region V there are twenty-three Independent Living Centers funded by the authority of Section 711 (Title VII, Part B) of the Rehabilitation Act of 1973, as amended. Their programs are dedicated to the development and provision of a variety of services which will assist severely handicapped persons to realize the goal of maximum individual independence. Consequently, the programs have been developed to serve the most significant identified needs of disabled consumers in each community. This grass-roots response to particular needs has provided a rich and diverse offering of special services within Region V.

A lengthy and individual description of each program would be necessary to depict completely the total independent living effort in the states of Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin; therefore, only some general characteristics of the centers are provided.

Most of the centers receive Rehabilitation Services Administration (RSA) grant funds on a contract basis from the State Vocational Rehabilitation agencies. In all states but Indiana, the state agency is the recipient of the RSA grant. In the two state agencies serving the blind and visually impaired (Michigan Commission for the Blind and Minnesota State Services for the Blind), direct administration of center programs is maintained.

The majority of centers in Region V are consumer-based, consumer-managed and consumer-staffed. Many are free-standing private, not-for-profit corporations and are not affiliated

with established organizations or agencies. Several have organizational relationships with established rehabilitation centers or other rehabilitation organizations. In one instance the affiliation is with a state university. In all centers there is preponderant consumer policy input and control in the administration of the programs.

The first center became operational in September, 1979 and all others received initial grant/contract funds in 1980 and 1981. The seven services most frequently offered are: information and referral; personal care attendant programs; peer counseling; housing assistance; transportation assistance; independent living skills and advocacy services.

A wide range exists in size of staff, funding levels, number and types of disabilities served, services provided and other characteristics. Nowhere is the extent of that range more clearly shown than in staffing statistics. Full-time staff totals range from one center with 21 to one center with none. The average is about five to a center. The utilization of part-time employees shows a maximum of eight in one center to--once again--one center with none. On average, there are fewer than two part-time staff persons to a center.

The following tables show sources and levels of support:

Table I

Funding Source*	
Title VII, Part B	23
State funds	9
Private funds	8
Other	7

* Total exceeds 23 because some centers have multiple sources of support

Table II

Annual Budget	
Up to $30,000	1
$30,000-60,000	5
$60,000-100,000	6
$100,000-200,000	8
Over $200,000	3

The following information, provided through one state's assessment of the five centers under its contract management during a six-month period, is not necessarily representative, but may be useful in understanding the nature and especially the scope of center activities.

Of a total of 799 consumers who came to the centers for services, 301 were served and terminated and 394 remain for more prolonged assistance. The others withdrew before any service was given. Following are several characteristics of these persons and their distribution as a percentage of the total group served:

Table III

Major Services Provided

Service	Percent
Housing	19.0
Community living skills	14.0
Attendant care	8.0
Leisure & recreation	7.0
IL skills	7.0
Transportation	7.0
Peer/family counseling	6.0
Health maintenance	6.0
Pre-voc./vocational	6.0

Table IV

Disabilities Served

Disability	Percent
Visually impaired	5.3
Hearing impaired	8.5
Cerebral palsy	10.9
Cardiac conditions	8.0
Spinal cord injury	17.7
Arthritic/rheumatic/ other orthopedic	6.6
Mental retardation	3.3
Mental illness	2.1
Other	37.6

Most of those served (83%) ranged in age from 20-69. The largest sub-group (26%) were 20-29 years old, clearly an optimum age-range for maximum long-term benefits to society.

Table V

Education (Years of school)

5-8 years	13.0
9-12 years	58.0
13-16 years	24.0
Not reported	5.0

Of those served, 66.7% were considered to have shown improvement at time of closure, 26.5% were not improved and improvement could not be determined for 1.3%. In 5.5% of cases improvement was not a reported item.

Of considerable significance were changes in residential status during the course of service:

Table VI

Status	Percent at Referral	Percent at Closure	Difference
Hospitals/alcohol/ drug centers	10.5	4.9	- 5.6
Nursing homes	7.6	6.3	- 1.3
Community residential facility	2.0	1.0	- 1.0
Special arrangements	.8	1.3	+ .5
Parent/relative's home	22.0	12.0	-10.0
Own home	52.0	68.0	+16.0
Unreported	5.1	6.5	

While most of the reductions in the right-hand column indicate only modest improvements in clients' living situations, the large increase in the "own home" category represents one of the major triumphs of the independent living program. The movement of disabled persons from dependent life-styles to independence is nowhere more dramatically shown than here.

This brief description of some characteristics and benefits of independent living centers provides only a "snapshot" of the activities and programs currently in operation in Region V. It is intended to be only an informational starting point; a more comprehensive and sophisticated analysis of the programs and outcomes must await the development and implementation of a uniform data base. Other human service programs have taken years to develop and refine a useful data base. This makes it more remarkable, then, that programs of independent living which have existed for only two to three years can show evidence of such substantial progress despite extremely limited resources.

The vignettes that follow are true stories about real people. Reading them will give a vivid picture of the human aspect of independent living services--essentially what the program is all about.

Dan became a quadriplegic at age 17 because of an automobile accident. Following lengthy physical rehabilitation he returned home, where his over-solicitous-family prevented him from using the skills he had learned during the rehabilitation process. His feeling of uselessness increased to the point that he became suicidally depressed.

Through the help of the State Vocational Rehabilitation (VR) agency Dan was able to complete high school work and receive his certificate of General Education Development (GED). Subsequently he was evaluated and judged to have little vocational potential.

After a time Dan made an attempt to live on his own, but through lack of sufficient self-care knowledge he developed severe decubitus ulcers and was forced to return to a full-care situation. Because he thought it would be less restrictive than being with his family he chose a nursing home, but soon found there was little difference.

About a year ago Dan learned about the CIL in his city through publicity about the center's outreach program. The staff there provided independent living skills training and counseling to motivate him to adhere to his mandatory self-care program. They also located an accessible apartment, federally-subsidized through Section 8 of the Housing Assistance Payments Program for Lower-Income Families, U. S. Department of Housing and Urban Development and found a suitable personal care assistant.

Despite his limited physical function, Dan has been living independently for some time, requiring only minimal assistance

in performing the necessary physical and logistical tasks. He also has become a volunteer for the center, working as a peer counselor and providing orientation to PCA trainees, activities that have increased his sense of personal worth.

With the encouragement of a center staff member Dan, now 34, has decided to enroll in the local community college to work toward a degree as a paraprofessional in human services. Thus, through services provided by a center by independent living, this young man's life has been completely turned around. From a totally dependent, depressed individual with little to look forward to, he has become a contributing member of society, with better days ahead.

Dan himself describes the difference this way: "I have the freedom to use my mind again and make my own decisions, right or wrong."

LAST YEAR		THIS YEAR	
SSDI*	$ 2,340	SSDI	$ 2,340
Medicaid	600	Personal care assistant	4,342
Nursing home	14,965		
		Medicare/Medicaid (Medicine, wheelchair etc.)	700
		Rent (subsidy)	3,600
Total	$ 17,905	Total	$ 10,982
		Difference	$ 6,923
			-39%

* Social Security Disability Insurance

Emily, who is mentally retarded and has severe visual impairment, was graduated from high school after completing a special education curriculum. During her school years she lived in several foster homes; after graduation she went to live in the county health care center.

Less than a year ago, a university-affiliated independent living program selected 21-year-old Emily for training to live in a partially independent environment. She now lives and actively participates in a cooperative housing arrangement in which three developmentally disabled clients and two university students share common household duties and assume responsibility for their personal tasks, such as cooking and laundry. The students serve as role models and provide crisis intervention.

She has also been admitted to a sheltered workshop, where she is receiving pre-vocational training. Emily's potential is now judged to be such that after another year to a year and a half of developing good work skills and appropriate social behavior she will be a good candidate for competitive employment.

On-going counseling and training in such independent living skills as money management and budgeting, cooking, using public transportation and planning use of leisure time have increased Emily's sense of personal worth and greatly improved her quality of life. Those who are working with her anticipate that after perhaps two years in her present living and working situation she will be capable of living as an independent individual.

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LAST YEAR		THIS YEAR	
SSI*	$ 4,608	SSI	$ 4,608
Health care center	14,027	Medicaid	144
		Sheltered workshop wages	192
Total	$ 18,635	Total	$ 4,944
* Supplemental Security Income		Difference	$ 13,691
			-73%

Severely disabled by cerebral palsy, Norman lived at home, where his mother provided the full range of personal care and daily living services. Although he attended special schools he never learned to read and his parents did not encourage him to become involved in any community activities.

When Norman reached age 21 he moved to a nursing home in an attempt to become more independent. That this course of action did not satisfy his needs is obvious; in ten years he lived in eleven different nursing homes. He also made one brief try at apartment living, but lacking survival skills he was forced to return to the home.

About a year ago Norman came to the independent living center in his city for help with still another venture at living on his own. The staff assessed his multiple needs: training in personal care and independent living skills; learning to read; financial assistance and accessible housing.

He was referred to the occupational therapy program at a rehabilitation hospital, where he was trained in the use of adaptive equipment to enhance his daily living skills. At the center Norman attended a number of independent living seminars, covering such topics as human potential; personal care assistant (PCA) management; self-help aids in homemaking; self-image and sexuality; and nutrition.

Within three months he was able to move into a supportive living arrangement and now shares a federally-subsidized apartment with another disabled man. He has hired and manages a PCA

who supplies personal care and homemaking services. By attending a center program of services for work and rehabilitation he is continuing to upgrade his independent living skills, he is learning to read and is receiving pre-vocational training.

Moving from a dependent environment to his present situation has given Norman an appreciation of his freedom to establish social relationships by getting out in the community. He now has goals: to complete a high school equivalency program and get his GED, and some day to obtain competitive employment.

Norman's definition of independent living: "To work and live on my own."

LAST YEAR		THIS YEAR	
SSDI	$ 4,992	SSDI	$ 4,992
Nursing home (Medicaid)	10,450	Personal care assistant	6,114
Hospital (Emergency care)	4,400	Medicaid/Medicare (Wheelchair repair, medicines, etc.)	300
Wheelchair costs	300	Rent (subsidy)	2,948
Total	$ 20,142	Total	$ 14,354
		Difference	$ 5,788
			-29%

Melanie, 42, has a long history of mental illness for which she has been hospitalized numerous times. Two years ago she was released from a state hospital psychiatric ward with few survival or coping skills and encountered severe financial and interpersonal problems.

Initially she came to the CIL for assistance in resolving a dispute with her landlord. Staff then helped her to be assigned to a different psychologist at the local mental health center. Further efforts on Melanie's behalf have included money management and assertiveness training and other related independent living skills. She is learning how to take charge of her life: to be responsible for monitoring her physical health, to recognize when she needs professional help for emotional problems--and to get it.

Melanie has been married and divorced and receives $250 a month in alimony. This is her only income, as this amount has made her ineligible for any public assistance--Medicaid, SSI or food stamps. She stretches her meager income by sharing living quarters with three other mentally or physically disabled persons and by canning much of her own food from end-of-the-day giveaways at the local farmers' market. For a little additional cash she scavenges pop-top cans to sell for recycling; except that she has a place to live, she could be called a "bag lady."

Probably it is through the intervention and support services she has received from the center that Melanie has been able to survive outside of an institution. Even discounting her personal preference for living independently, albeit in poverty, Melanie's experience is a real "success story" for the taxpayers. The cost comparison below shows dramatically the benefits to society realized through CIL services.

TWO YEARS AGO		THIS YEAR	
State hospital (custodial care)	$ 30,002	Counseling (Social worker at welfare office, est.)	$ 720
Psychiatric care/ medications	13,433		
Total	$ 43,435	Total	$ 720
		Difference	$ 42,715
			-98%

Injuries sustained in an automobile accident seven years ago left William a quadriplegic. He was 14 years old.

After finishing school he became a client of the State rehabilitation agency and successfully completed training as a computer programmer. He obtained employment in that field and bought a van which was fitted with adaptive aids by the VR agency. This enabled him to get to and from work independently.

Because he was unaware of other options, through these years William continued to live in the family home, with his father supplying the needed attendant care. About a year ago, at the suggestion of a family member, William came to the CIL in his city to explore the possibilities for living more independently.

The center provided referrals to varied sources of help: affordable, accessible housing; a credit agency for a loan for initial expenses of establishing his own residence; possible avenues for locating personal care assistants.

For almost a year now, William has been living in a barrier-free, Section 8, federally-subsidized apartment, with a live-in personal care assistant on a room-and-board-for-services arrangement. He is also becoming active socially; one of his greatest pleasures is going camping with his girlfriend.

While there is no direct, immediate dollars-and-cents benefit to taxpayers in this story, benefits to society are incalculable--and obvious: William, at age 21, has progressed to a higher

level of independence through the services of a CIL and will have a productive, self-reliant life. As his skills and income increase, the present taxpayer subsidies will no longer be necessary. His family, especially his father, surely is pleased at his present accomplishments and his brighter future, as well as relieved of a physical burden that would have become increasingly difficult to sustain as the years pass.

Marjorie is 32 years old and has a progressive neuromuscular disease which so far has defied precise identification. The disorder has forced her to use a wheelchair for the past four or five years.

When she first learned about the CIL in her city she was living in an unsuitable apartment, had no knowledge of available transportation services, had no plans or goals and was extremely depressed.

Since utilizing the center's services Marjorie's life situation has undergone a striking change. She now lives in a Section 8, federally-subsidized, accessible apartment; through counseling she became aware of her rights as a disabled citizen and is an effective self-advocate; she has learned about and frequently uses the city's bus service for the handicapped; she has enrolled in junior college to become an occupational therapy assistant; to the degree her physical condition permits she is active in a sports program at the center; and she contributes as a volunteer to the center, working on the newsletter and doing telephone research to locate accessible housing for other CIL clients.

In this story about Marjorie it is difficult to present accurate before-and-after costs. Some "before" information is not available, e.g., medical and surgical costs paid through Medicare/Medicaid. Certain "after" costs are difficult to assess

also, such as how much Marjorie's use of the bus system costs the city, or the total financial assistance she receives from the junior college, both in tuition and Handicapped Student Services time.

While it would be gratifying always to be able to point to substantial dollar savings, at times there may be either a trade-off or even an increase of costs through the intervention of independent living specialists. In Marjorie's case this may be a short-term increase in order to get eventual long-term reduction of taxpayer burden. However, as the comparison below shows, the progressive nature of her disease has required additional services (homemaker care).

Even if her future condition calls for still more assistance, as long as Marjorie can remain in her own apartment her total maintenance cost will be substantially lower than that in a nursing home, which would total, at a minimum, $18,000 to $20,000 annually.

LAST YEAR		THIS YEAR	
SSI	$ 3,708	SSI	$ 3,708
Homemaker care	-0-	Homemaker care	3,360
Rent (subsidy)	2,376	Rent (subsidy)	3,132
Total	$ 6,084	Total	$ 10,200
		Difference	$ 4,116
			+68%

Because of severe cerebral palsy, Lillian had spent the last 14 years in a nursing home. Eight months ago, at age 39, she requested admission to a center for independent living. This CIL is associated with a rehabilitation institute (part of a major urban medical center), and offers residential services and training.

Lillian's strong motivation and eagerness to learn practical, fundamental skills enabled her to make rapid progress and to gain needed confidence and self-reliance. After two months, she had acquired such personal care competence that her need for assistance was reduced by half. Indeed, she progressed so rapidly that she completed the usual six-month course in four months.

In spite of extreme spasticity, Lillian gained independent living skills to such a degree that she is now living in a federally-subsidized (Section 8), barrier-free apartment, virtually independent. Her only needs are part-time personal care assistance and help with heavy housecleaning.

The CIL provided services and training in the whole range of independent living skills, among them cooking; cleaning; personal care assistant management; health and hygiene; leisure planning; assertiveness and advocacy training; and physical fitness. Having achieved such competence in daily living, Lillian is now receiving help in remedial reading and writing and is looking toward the possibility of vocational training some time in the future.

This account of how Lillian moved from complete dependency to virtual autonomy, with every reason to hope for a better future, is a success story about society's care of the less fortunate. However, society is also concerned about what it costs to achieve these triumphs. The chart below gives striking evidence that in many cases it is not only socially, but also fiscally desirable to make such successes possible. Finally, no matter which way the benefits may be viewed, if Lillian were asked she might say that for her, Life Begins at Forty.

LAST YEAR		THIS YEAR	
SSDI	$ 3,720	SSDI	$ 3,984
Medicaid	6,012	Personal care assistant (15 hrs/wk)	2,478
Nursing home	14,950		
		Rent (subsidy)	3,204
Total	$ 24,682	Total	$ 9,666
		Difference	$ 15,016
			-61%

Walter, who is legally blind, lives with his wife in a senior citizens apartment complex. Within the last year his need for cataract surgery became acute--he could distinguish only between light and dark--and his hearing deteriorated to almost total deafness.

Because of his limited income, Walter could afford neither the cataract surgery, estimated to cost about $2,500, nor a new hearing aid at approximately $200. The combined handicaps obviously presented serious obstacles to physical and social functioning. Lacking improvement in his condition, a move to a nursing home seemed almost inevitable.

At this point the CIL in his city became involved. The staff obtained diagnostic evaluations and for $229 purchased a hearing aid which brought Walter's hearing up to normal. The center also secured financial assistance totaling $700 from the local Lions Club to supplement the Medicaid payments for surgeon's fee and hospital costs for the cataract surgery.

As a result of these services Walter is functioning quite independently; even if his wife could no longer help him he would probably be able to remain in his own home. His improved condition has also enabled him to resume his former leadership position in the organization for the blind in his city.

Thus, through the expenditure of $812 from the center (hearing aid and diagnostic tests) and $700 from the Lions Club (cataract surgery), a previously active and involved older citizen was enabled to become so again. In addition, by

virtually eliminating the need for institutional care, the center, through its efforts, has achieved significant cost avoidance: a conservative estimate places the cost of such care at no less than $16,000 a year.

Jennifer is a young woman of above-average intelligence who has moderately severe speech and mobility problems because of cerebral palsy. She does not articulate clearly and uses a walker. These limitations made her unsure of her ability to succeed in college, so after graduation from high school she remained at home and entered a sheltered workshop program, doing general office work.

Nearly a year ago she attended a workshop on independent living at the local CIL. Meeting and talking with other attendees, some more severely disabled than she, Jennifer realized that taking charge of her own life and taking risks was something she could do. She began by inviting other disabled persons to join with her in a social club and she received a positive response. From this she has progressed to training in the center's peer counseling program, with emphasis on social and recreational program ideas.

The encouragement the center has given Jennifer has enabled her to take a big step forward. This fall, at 26, she enrolled in a nearby college, with a tentative career goal of rehabilitation counseling. Every day brings more self-confidence as Jennifer learns how to make adult, independent decisions about herself--now and for the years to come.

Cost savings are difficult to compute. Jennifer will remain at home for the present; since she has been in a subsidized workshop and is receiving financial assistance in college, taxpayer costs will probably remain fairly constant.

However, her future earning power will be substantially greater after achieving a college education, so she can become a fully contributing member of society.

Inevitably, Jennifer's parents will some day be unable to take care of her. And then, lacking survival skills, she would be completely dependent on custodial care in an institution. However, with the impetus and training furnished by the center, she has taken the risk to develop her potential--and she can face the future with optimism.

As the result of an automobile crash on his high-school graduation night, Tim has been a quadriplegic for 23 of his 40 years. After a fall early this year, he was hospitalized for six months. When he was ready for discharge he had nowhere to go, as his room in a group home was no longer available.

There were several obstacles to be overcome at that time. Because he no longer required medical care Tim had to leave the hospital within two weeks; the hospital was 100 miles distant from his home city, making the housing search more difficult; if no suitable housing could be found, the only alternative was placement in a nursing home, a solution previous experience had made unacceptable to him because of "age difference and emotional trauma," in his words.

At this point, Tim was referred to the CIL in his city. In a race against time, center staff obtained an accessible unit in a newly-opened federally-subsidized housing complex and helped Tim move in a day ahead of the hospital discharge deadline. Subsequently they helped him find permanent live-in attendants and obtain Title XX (Social Security Medicare) funds to pay for housekeeping services in his apartment.

At one time Tim had operated a small business, but when that was no longer feasible, the State Division of Vocational Rehabilitation made it possible for him to attend college.

He is majoring in rehabilitation counseling and expects to get his bachelor's degree in about two years.

The figures below show substantial current cost reductions in Tim's living situation achieved through the CIL's efforts. It is also clear that in the future, because of services he is receiving from DVR, Tim will become a truly independent, tax-paying citizen.

LAST YEAR		THIS YEAR	
SSI/SSDI	$ 3,648	SSI/SSDI	$ 3,648
Nursing home care	29,172	Rent (subsidy)	3,600
Medications	780	Attendant care	12,000
		Chore services	6,000
		Medications	540
Total	$ 33,600	Total	$ 25,788
		Difference	$ 7,812
			-23%

Howard's elderly parents, in failing health, were concerned about his future when they could no longer provide around-the-clock care for him. Mentally retarded and with multiple physical problems, 46-year-old Howard had lived at home all his life.

When his family enlisted the assistance of the local CIL nearly a year ago, it was clear that Howard needed the full range of its services, as family members had relieved him of all responsibility for his own survival duties. Staff at the center located an accessible, federally-subsidized apartment and trained Howard in the daily living skills he needed to maintain himself in it. He also learned to use the city transportation system and to do his own shopping. Functioning at a higher level than ever before, Howard has established social relationships with his neighbors and participates in a bowling league.

While he has never been employed and vocational prospects are not bright at present, his marked improvement in social functioning and competence in living independently suggest the possibility that a vocational goal may be attainable one day.

Whatever the future may bring, Howard's family are relieved that he is now in a suitable living situation and competently managing his own affairs. Indeed, one family member, impressed with the value of the CIL, has become a volunteer, locating housing for center clients.

Although the cost comparison below shows a present increase, it is minimal compared to what it would be if Howard, lacking independent living skills, were forced to enter a nursing home for custodial care. Present cost of maintenance in an intermediate care facility is conservatively estimated at $15,000 to $20,000 annually.

LAST YEAR		THIS YEAR	
SSI/SSDI	$ 5,052	SSI/SSDI	$ 5,052
Rent (subsidy)	-0-	Rent (subsidy)	3,552
Medical care (covered by family policy)	-0-	Medicaid	384
Total	$ 5,052	Total	$ 8,988
		Difference	$ 3,936
			+78%

Suzanne has been paralyzed on the right side of her body following a stroke 13 years ago. She has been living in a nursing home ever since, confined to a wheelchair. She is very soft-spoken and has some speech difficulties.

Although she has independent living skills, and at first thought she wanted to attempt apartment living with a personal care attendant and homemaker services, Suzanne, now 55, felt unsure of her abilities after so many years of dependency. For the present, therefore, she opted for a transitional living situation, with roommates who are also disabled. Attendant care and homemaker support are available around the clock.

The center gave her information on housing and attendant care possibilities; the center worker thinks that in a year or two she will quite likely be on her own, as her feeling of capability increases. A measure of Suzanne's growing self-confidence is that her reluctance to use the phone because of her speech problems seems to be lessening. As her speech improves, she uses the phone more and more, one indication of life-quality improvements attributable to independent living services.

LAST YEAR		THIS YEAR	
SSDI	$ 420	SSDI	$ 3,408
Nursing home	17,338	Attendant care	10,800
		Medicaid (medicine)	480
		Rent (subsidy)	852
Total	$ 17,758	Total	$ 15,540
		Difference	$ 2,218
			-13%

Despite the effects of multiple sclerosis, which have left her legally blind and a double amputee confined to a wheelchair, Myra has maintained her independence and lives alone in her own home. She must also cope with many other medical problems, including pulmonary difficulties that are aggravated by heat and humidity. To enable her to remain at home, her doctor recommended the installation of a room air conditioner.

As a client of the State Commission for the Blind, learning handicraft and homemaker skills, Myra tried first to obtain the appliance through that agency. However, the equipment was not deemed necessary for her to complete her program and achieve her vocational goal.

Myra then turned for help to the CIL in her community, as the "agency of last resort." Staff there were able to obtain funding from the National Multiple Sclerosis Society for two-thirds of the cost of the air conditioner, with the Commission for the Blind supplying the balance. Through the CIL's timely intervention and imaginative approach to locating the resources, Myra was able to remain in her home and continue her rehabilitation plan without undue stress during the hot and humid months.

Thus a total expenditure of $460 for the air conditioner ($295 from MS, $165 from the State agency) helped an independent, 39-year-old woman remain so, to her own and society's

benefit. The comparative chart below snows approximate maintenance costs for Myra in her own home versus what it would cost, likely for many years, had she been forced to move to a nursing home. Thus, this success story is not one of cost-reduction, but of cost-avoidance.

DEPENDENT		INDEPENDENT	
Social Security (survivor's benefits)	$ 4,068	Social Security (survivor's benefits)	$ 4,068
Nursing home (Medicaid, incl. supplies/medicine/ doctor)	11,940	Medicaid (supplies, medicine/doctor)	1,800
		Homemaker assistance	2,520
Total	$ 16,008	Food stamps	432
		Total	$ 8,820
		Difference	$ 7,188
			-45%

When Ethel was six years old she became a quadriplegic as the result of an attack of polio. After finishing high school she became a client of the State Vocational Rehabilitation agency and completed university training as a rehabilitation counselor. Throughout these schooling years she lived at home, where her mother attended to her personal care needs, encompassing the full range--bathing; dressing/undressing; bed and wheelchair transfers; meal preparation; housekeeping; transportation, etc.

About a year and a half ago Ethel, then 33, found a counseling position that made it necessary for her to move from her parents' home to an apartment closer to her job. At her request, the CIL in her city helped her to locate an accessible apartment and subsequently was instrumental in finding appropriate candidates to satisfy her need for a permanent personal-care assistant.

Ethel's income is too high for her to receive Medicaid/Medicare services, so the center's attendant care coordinator explored other options with her. She then found a suitable live-in attendant in exchange for room and board plus much free time during the day.

In addition to supplying her housekeeping, health and personal hygiene needs, Ethel's attendant drives her to and from work in the used, fully-equipped van Ethel has purchased from her earnings.

This up-beat story is one to hearten everyone in the social service field, and to encourage the heavily-burdened taxpayer as well. Without the support and training supplied by VR and the services and creative alternatives offered by the center for independent living, this severely-disabled woman would probably have spent her life completely dependent on her family--and later, the taxpayers. Instead, Ethel is a contributing, tax-paying member of society, successfully leading an independent life.

	DEPENDENT	INDEPENDENT
SSI	$ 3,000	None
(No other taxpayer costs, as she lived with her parents.)		

Anna, who is in a wheelchair, was living in a county medical care facility because of multiple physical handicaps--diabetes, severe visual problems and suspected multiple sclerosis. About a year ago, at age 37, she decided to make an effort to become more independent, and requested help from the CIL in her city. The staff furnished training in independent living skills, much needed because she had never lived alone, helped her to locate an accessible apartment and made sure she received a low-vision evaluation.

Anna is now living on her own in an accessible apartment, doing her own cooking and most of the cleaning, administering her own medication, handling her personal finances, and performing other tasks appropriate to living independently. Although her vision is still very limited, her functioning has greatly improved because she has three new pairs of glasses. These were acquired through the efforts of the CIL, which obtained financial support of $400 from the local Lions Club. In short, Anna is living virtually on her own, with some assistance in transportation and shopping supplied by friends.

She is also active in her church, running Sunday School sessions and helping with Bible study classes. Anna plays the piano and with a musical group regularly visits several nursing homes to entertain the patients. She began a steady babysitting job this fall and is carrying out those duties satisfactorily.

Anna's story is unquestionably impressive: within one year moving from total dependency in a nursing home environment to independence--a woman in charge of her life, living alone, helping others and gainfully employed. This is not only a success for Anna, but one for the taxpayers, too, as a reading of the figures below will demonstrate.

LAST YEAR		THIS YEAR	
SSDI	$ 324	SSI/SSDI	$ 3,912
Care facility (Medicaid/Medicare)	22,630	Medicaid (medicines/doctors)	780
Total	$ 22,954	Medicare	132
		Rent (subsidy)	1,440
		Food stamps	132
		Total	$ 6,396
		Difference	$ 16,558
			-72%

On crutches because of cerebral palsy, Betsy, 24, successfully completed college with a bachelor's degree in paralegal studies. Since no jobs were available in her small town, last spring she moved to a nearby large city and requested information on housing and transportation from the CIL there.

Among the services Betsy received were assistance in locating an accessible federally-subsidized (Section 8) apartment, information on the city's bus system for the handicapped, and referral to the State DVR for job training and job placement services.

Having completed the center's training program, Betsy is volunteering as a peer visitor. Now she has started training to learn to counsel center clients in their search for accessible, affordable housing. This will give her a paid, part-time position that will provide valuable work-experience and needed additional income.

At present the state of the economy presents obstacles to Betsy's placement in a position in the paralegal field for which she trained. However, living in a large city gives her the opportunity to take advantage of any openings that may occur. In the meantime, as a satisfied former client, she is contributing skill and enthusiasm to the center, while acquiring useful experience.

While the comparison below does not show an immediate taxpayer benefit, Betsy's improved living situation and availability for future paraprofessional employment counterbalance the temporary increase.

LAST YEAR		THIS YEAR	
SSI	$ 3,180	SSI	$ 3,180
Total	$ 3,180	Rent (subsidy)	2,808
		Total	$ 5,988
		Difference	$ 2,808
			+88%

Mildred spent 20 of her 35 years in a state mental institution, classified as mildly to moderately retarded (mostly institutional retardation) and with emotional problems as well. When she was released about two years ago she had little or no knowledge of how to live "outside." As might be expected, she had many problems with obtaining needed services and establishing friendly social relationships.

After moving to a different city Mildred was totally indigent and lived on park benches--a "bag lady." Later, through the intervention of the person who was designated to manage her social security income on her behalf, she moved into a boarding home. There, with help from the local CIL, she began to learn to manage her money and cook her own meals. As Mildred's skills and self-confidence grew, it was clear she had the capability to live alone. Soon she moved to a federally-subsidized (Section 8) apartment where she is managing to solve her problems--with minimal assistance from the CIL--and is handling her own finances.

At this point Mildred is being tested and evaluated by the State VR agency to assess her capability for employment. She continues to receive counseling through community mental health services, has attended adult basic education classes and is planning to participate in Special Olympics.

She also volunteers at two nursing homes, serving meals and contributing other assistance to the residents.

While the chart below shows no present savings to taxpayers (instead there is an increase) Mildred's experience is a striking example of how a severely disabled person can move from long-term institutionalization and no apparent vocational potential to an independent lifestyle with a good prospect of future employability. When the day comes that Mildred can convert her volunteer services to paid employment, the taxpayers stand to reap a substantial return on society's investment in her.

LAST YEAR		THIS YEAR	
SSI	$ 3,307	SSI	$ 3,468
Medicaid	500	Rent (subsidy)	1,344
Food stamps	288	Food stamps	288
Total	$ 4,095	Total	$ 5,100
		Difference	$ 1,005
			+25%

Twenty-six-year-old Hazel is severely disabled by cerebral palsy. She gets around in a motorized wheelchair which was bought in anticipation of a move to independent living from the rehabilitation center which had been her home for almost two years. Prior to that she had been in a nursing home for seven years, after leaving her parents' home.

Less than a year ago, when she heard about the local independent living center through an outreach program, Hazel immediately requested their services. With the center's help she located an accessible apartment in a housing complex occupied by disabled persons and she has become active in a support group there. She also attends church regularly and goes shopping, community activities she was not able to participate in while living in a nursing home.

The center helped Hazel to learn budgeting and other independent living skills. Very important was counseling in how to structure her days, since a long-term nursing home resident has little idea of how to manage time when living independently.

According to a center staff member who has worked closely with her, Hazel is so severely disabled that she really should have a personal care assistant and homemaker services. However, she is strongly motivated and determined to do everything on her own--and against great odds she is managing successfully.

Hazel now volunteers 25 hours a week at the center, doing peer counseling and receiving on-the-job training in a variety of office skills. She makes phone calls to locate housing and other services for the center's clients, does filing and fills in as receptionist. Estimates are that Hazel will soon be able to work 30 hours a week, using the vocational skills she has been learning, and within five years she will probably be able to work a full 40-hour week in competitive employment.

LAST YEAR		THIS YEAR	
SSDI	$ 420	SSDI	$ 3,408
Rehabilitation Center	32,850	Motorized wheelchair*	660
		Medicare (wheelchair repair)	300
Total	$ 33,270	Rent (subsidy)	2,196
		Total	$ 6,564
		Difference	$ 26,706
			-80%

* Wheelchair purchase $3,300, average life 5 years. Annual cost $660

AFTERWORD

Human services providers and government agencies are constantly searching for ways to document reductions in taxpayer burden achieved as a result of their program efforts. Precise measurement of such economic benefit is a desirable but elusive goal. Despite the difficulties, however, these accounts demonstrate that significant individual and aggregate benefits are being provided to severely handicapped persons by the 23 Independent Living Centers in Region V.

Part of the difficulty arises from the large variety of problems and disabilities presented to the centers and the broad range of individualized services and programs needed to deal with them. Another obstacle exists simply because independent living is a new program, as social programs go, and has so far developed cost-benefit documentation methods of only limited scope and meaning. A universally-applicable system awaits longer experience and more sophistication in the program.

Our society is founded on certain intangible humanistic values, especially that of individual worth. For the independent living movement to reach its full potential and acceptance, the intangible benefits accruing through its efforts to individuals, families, communities--and the taxpayers--must be recognized. These benefits must then be included as part of the "bottom line" in any assessment of financial cost and benefit.

There is an interesting--and possibly unexpected--aspect of the independent living program emerging through these case histories. The movement was conceived as a means of assisting the isolated severely-disabled into the mainstream, even though no vocational goals seemed realistic. It is now becoming apparent that many heretofore unlikely candidates are moving into programs where employment may be attainable. Thus, this unanticipated development may prove to be one of the most valuable benefits of independent living services.

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